2023 Summary of Advances Nominations

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Screening and Diagnosis

	Screening and Diagnosis
NIMH	Nominated article:
	James S, Hallur S, Anbar J, Matthews N, Pierce K, Smith CJ. Consistency between
	parent report and direct assessment of development in toddlers with autism spectrum disorder and other delays: Does sex assigned at birth matter? <i>Autism Res</i> .
	2023 Jun;16(6):1174-1184. [PMID: 37009713]
	Justification from IACC member who nominated article:
	This study examined differences between how parents assess and measure their
	autistic child's development versus how diagnosticians (i.e., health providers) assess
	development, particularly language and fine motor abilities in toddlers. Also, this
	study looked at if a child's sex assigned at birth (SAB) influenced the parents' or
	diagnosticians' assessments of development. Results indicate that parent-report
	measures and diagnosticians' assessment may differ when measuring receptive
	language and fine motor skills, and that child SAB appears to influence parent and
	diagnostician assessment for expressive language. Understanding how SAB might
	influence a parent's impression of various aspects of development, and how these
	impressions may differ to pediatric health providers' clinical impressions, could help
	improve early ASD screening, diagnosis, and intervention for both boys and girls.
NIMH	Nominated article:
	Jones W, Klaiman C, Richardson S, Lambha M, Reid M, Hamner T, Beacham C, Lewis
	P, Paredes J, Edwards L, Marrus N, Constantino JN, Shultz S, Klin A. Development and
	Replication of Objective Measurements of Social Visual Engagement to Aid in Early Diagnosis and Assessment of Autism. <i>JAMA Netw Open</i> . 2023 Sep 5;6(9):e2330145.
	[PMID: 37669054]
	Justification from IACC member who nominated article:
	This study sought to develop an objective performance-based tool to aid in early
	diagnosis and assessment of autism in children younger than 3 years. Researchers
	developed an objective eye-tracking-based index test for children aged 16 to 30
	months, compared its performance with best-practice reference standard diagnosis
	of autism (discovery study), and then replicated findings in an independent sample
	(replication study). Discovery and replication studies were conducted in specialty
	centers for autism diagnosis and treatment. In these studies, objective eye-tracking-
	based measurements of social visual engagement correlated with expert clinical
	diagnostic status as well as individual levels of social disability, verbal ability, and
	nonverbal ability in autism. These findings suggest that objective measurements of
NUNALI	social visual engagement can be used to aid in autism diagnosis and assessment.
NIMH	Nominated article: Pham C, Bacon EC, Grzybowski A, Carter-Barnes C, Arias S, Xu R, Lopez L, Courchesne
	E, Pierce K. Examination of the impact of the <i>Get SET Early</i> program on equitable
	access to care within the screen-evaluate-treat chain in toddlers with autism
	spectrum disorder. <i>Autism</i> . 2023 Aug;27(6):1790-1802. [PMID: 36629055]
	Justification from IACC member who nominated article:
	Delays in autism identification and access to care could impact developmental
	Delays in autism identification and access to care could impact developmental outcomes. Children from historically underrepresented minority backgrounds are
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detection programs such as Get SET Early that standardize these steps are effective at addressing disparities. As part of the Get SET Early model, primary care providers administered a parent-report screen at well-baby examinations, and parents designated race, ethnicity, and developmental concerns. Toddlers who scored in the range of concern, or whose primary care provider had concerns, were referred for an evaluation. Age at screen, evaluation, and treatment engagement and quantity was compared across groups. No differences were found in the mean age at the first screen, evaluation, or initiation or quantity of behavioral therapy between participants. However, children from historically underrepresented minority backgrounds were more likely to fall into the range of concern on the parent-report screen, their parents expressed developmental concerns more often, and pediatricians were more likely to refer for an evaluation than their White/Not Hispanic counterparts. This study suggests that models that support transparent tracking of steps in the screen-evaluation-treatment chain and service referral pipelines may be an effective strategy for ensuring equitable access to care for all children.

NIMH

Nominated article:

Shuster CL, Sheinkopf SJ, McGowan EC, Hofheimer JA, O'Shea TM, Carter BS, Helderman JB, Check J, Neal CR, Pastyrnak SL, Smith LM, Loncar C, Dansereau LM, DellaGrotta SA, Marsit C, Lester BM. Neurobehavioral and Medical Correlates of Autism Screening: 2-Year Outcomes for Infants Born Very Preterm. *J Pediatr*. 2023 Sep;260:113536. [PMID: 37271496]

<u>Justification from IACC member who nominated article:</u>

This study sought to identify neonatal characteristics and 2-year neurodevelopmental outcomes associated with positive screening for risk of autism. Nine university-affiliated neonatal intensive care units (NICUs) enrolled infants born at <30 weeks of gestation. Infants underwent the NICU Network Neurobehavioral Scale examination before discharge and the Bayley Scales of Infant and Toddler Development, Third Edition, the Child Behavior Checklist, and the Modified Checklist for Autism in Toddlers, revised with follow-up (M-CHAT-R/F). The findings showed that neonatal neurobehavior and medical morbidities were associated with positive M-CHAT-R/F screens at age 2 years in toddlers born very preterm. These findings demonstrate the potential utility of the M-CHAT-R/F as a global developmental screener in infants born very preterm, regardless of whether there is a later autism diagnosis.

Biology

NIMH

Nominated article:

Schwartz S, Wang L, Uribe S, Shinn-Cunningham BG, Tager-Flusberg H. Auditory evoked potentials in adolescents with autism: An investigation of brain development, intellectual impairment, and neural encoding. *Autism Res.* 2023 Sep 21. [PMID: 37735966]

Justification from IACC member who nominated article:

Limited research has evaluated neural encoding of sounds from a developmental perspective in individuals with autism, especially among those with intellectual disability. Researchers compared auditory evoked potentials (AEPs) in autistic adolescents with a wide range of intellectual abilities to both age-matched

cognitively able neurotypical (NT) adolescents and younger neurotypical children to assess potential developmental delays. Researchers found that peak amplitudes of neural responses were significantly smaller in autistic adolescents compared to neurotypical adolescents. Results suggest that AEPs of autistic adolescents present differently from NTs, regardless of age, and differences cannot be accounted for by developmental delay. Nonverbal intelligence significantly predicted how closely each adolescent's AEP resembled the age-normed waveform. These results support an evolving theory that the degree of disruption in early neural responses to lowlevel inputs is reflected in the severity of intellectual impairments in autism. **NICHD** Nominated article: St John T, Estes AM, Hazlett HC, Marrus N, Burrows CA, Donovan K, Torres Gomez S, Grzadzinski RL, Parish-Morris J, Smith R, Styner M, Garic D, Pandey J, Lee CM, Schultz RT, Botteron KN, Zwaigenbaum L, Piven J, Dager SR; IBIS Network. Association of Sex With Neurobehavioral Markers of Executive Function in 2-Year-Olds at High and Low Likelihood of Autism. JAMA Netw Open. 2023 May 1;6(5):e2311543. [PMID: 37140923] Justification from IACC member who nominated article: This study examined the interaction of sex, family likelihood of autism, and structural brain alterations on executive function (EF) deficits in toddlers (ages 24 months). EF (i.e., a set of high-level cognitive abilities that enable goal-directed behavior) was directly assessed in 110 participants with an older sibling with autism (high family likelihood or HL) and 55 with an older sibling without autism (low family likelihood or LL). Additionally, structural magnetic resonance imaging (sMRI) was performed to determine frontal, parietal, and total cerebral brain volume. Girls and boys at HL were found to have significantly lower EF than girls and boys at LL. In girls this difference persisted even when toddlers with autism were excluded. Also, EF performance deficits were associated with larger frontal lobe volume and smaller parietal volume, although EF was less sensitive to volume differences in girls at LL than in any other group. Future longitudinal studies are warranted to examine the effect of early EF deficits on later developmental outcomes. **NIMH** Nominated article: Waizbard-Bartov E, Ferrer E, Heath B, Andrews DS, Rogers S, Kerns CM, Wu Nordahl C, Solomon M, Amaral DG. Changes in the severity of autism symptom domains are related to mental health challenges during middle childhood. Autism. 2023 Sep 10:13623613231195108. [PMID: 37691349] Justification from IACC member who nominated article: For many autistic children, their autism traits may change during middle childhood. Researchers studied whether these changes are associated with the emergence of other mental health challenges such as anxiety and attention-deficit hyperactivity disorder. Children who had increased social-communication challenges had more anxiety and attention-deficit hyperactivity disorder symptoms and disruptive behavior problems than other children. Children who decreased their restricted and repetitive behaviors, on the contrary, had more anxiety. **NIMH** Nominated article: Wright N, Courchesne V, Pickles A, Bedford R, Duku E, Kerns CM, Bennett T, Georgiades S, Hill J, Richard A, Sharp H, Smith IM, Vaillancourt T, Zaidman-Zait A, Zwaigenbaum L, Szatmari P, Elsabbagh M; Pathways Team. A longitudinal

comparison of emotional, behavioral and attention problems in autistic and typically developing children. *Psychol Med.* 2023 Jun 29:1-13. [PMID: 37381780]

Justification from IACC member who nominated article:

Researchers sought to compare the level and growth of anxious-depressed, behavioral and attention problems in an autistic and typically developing (TD) cohort. The results showed that autistic children showed elevated levels of mental health problems, but this was substantially reduced by accounting for IQ and sex differences between the autistic and TD samples. Anxious-depressed problems were particularly elevated at preschool and attention problems at late childhood. Higher IQ predicted lower level of attention problems. Female sex predicted higher level of anxious-depressed and faster decline in behavioral problems. This study suggests that autistic children, especially girls, show elevated mental health problems compared to TD children and there are some differences in predictors. This study has implications for the assessment of mental health in clinical practice for autistic children.

Genetic and Environmental Factors

EPA Nominated article:

Carter SA, Rahman MM, Lin JC, Chow T, Yu X, Martinez MP, Levitt P, Chen Z, Chen JC, Eckel SP, Schwartz J, Lurmann FW, Kleeman MJ, McConnell R, Xiang AH. Maternal exposure to aircraft emitted ultrafine particles during pregnancy and likelihood of ASD in children. *Environ Int*. 2023 Aug;178:108061. [PMID: 37454628]

Justification from IACC member who nominated article:

There is increasing evidence for adverse health effects associated with aircraft-emitted particulate matter (PM) exposures, which are largely in the ultrafine (PM0.1) size fraction, but no previous study has examined neurodevelopmental outcomes. This study sought to assess associations between maternal exposure to aircraft ultrafine particles (UFP) during pregnancy and offspring autism spectrum disorder (ASD) diagnosis. This large, representative cohort study included 370,723 singletons born in a single healthcare system. Demographic data, maternal health information, and child's ASD diagnosis by age 5 were extracted from electronic medical records. Aircraft exposure estimates for PM0.1 were generated by the University of California Davis/California Institute of Technology Source Oriented Chemical Transport model. Increased risk of autism was associated with maternal exposure to aircraft PM0.1. The results strengthen the emerging evidence that maternal particulate matter exposure during pregnancy is associated with offspring ASD diagnosis and identify aircraft-derived PM0.1 as novel targets for further study and potential regulation.

EPA <u>Nominated article:</u>

Rahman MM, Carter SA, Lin JC, Chow T, Yu X, Martinez MP, Levitt P, Chen Z, Chen JC, Rud D, Lewinger JP, Eckel SP, Schwartz J, Lurmann FW, Kleeman MJ, McConnell R, Xiang AH. Prenatal exposure to tailpipe and non-tailpipe tracers of particulate matter pollution and autism spectrum disorders. *Environ Int*. 2023 Jan;171:107736. [PMID: 36623380]

Justification from IACC member who nominated article:

Traffic-related air pollution exposure is associated with increased risk of autism. It is unknown whether carbonaceous material from vehicular tailpipe emissions or

redox-active non-tailpipe metals, e.g., from tire and brake wear, are responsible. Researchers assessed autism associations with fine particulate matter (PM2.5) tracers of tailpipe (elemental carbon [EC] and organic carbon [OC]) and non-tailpipe (copper [Cu]; iron [Fe] and manganese [Mn]) sources during pregnancy in a large cohort. This retrospective cohort study included 318,750 children born in Kaiser Permanente Southern California (KPSC) hospitals during 2001-2014, followed until age 5. Results suggest that non-tailpipe emissions may contribute to autism. Implications are that reducing tailpipe emissions, especially from vehicles with internal combustion engines, may not eliminate autism associations with traffic-related air pollution.

NIMH

Nominated article:

Yap CX, Henders AK, Alvares GA, Giles C, Huynh K, Nguyen A, Wallace L, McLaren T, Yang Y, Hernandez LM, Gandal MJ, Hansell NK, Cleary D, Grove R, Hafekost C, Harun A, Holdsworth H, Jellett R, Khan F, Lawson LP, Leslie J, Levis Frenk M, Masi A, Mathew NE, Muniandy M, Nothard M, Miller JL, Nunn L, Strike LT, Cadby G, Moses EK; Busselton Health Study Investigators; de Zubicaray GI, Thompson PM, McMahon KL, Wright MJ, Visscher PM, Dawson PA, Dissanayake C, Eapen V, Heussler HS, Whitehouse AJO, Meikle PJ, Wray NR, Gratten J. Interactions between the lipidome and genetic and environmental factors in autism. *Nat Med*. 2023 Apr;29(4):936-949. [PMID: 37076741]

Justification from IACC member who nominated article:

In this study, researchers explored the plasma lipidome in 765 children (485 diagnosed with autism) within the Australian Autism Biobank. They identified lipids associated with autism diagnosis, sleep disturbances, and cognitive function and found that long-chain polyunsaturated fatty acids may causally contribute to sleep disturbances. Researchers then explored the interplay of environmental factors with neurodevelopment and the lipidome, finding that sleep disturbances and unhealthy diet have a convergent lipidome profile that is also independently associated with poorer adaptive function. In contrast, autism lipidome differences were accounted for by dietary differences and sleep disturbances. This study highlights the complex relationship between lipidomics and neurodevelopment, particularly in affecting the quality of life among autistic individuals.

Interventions

NIMH

Nominated article:

Clarke KA, Siegel M, Williams DL. The Relationship Between Augmentative and Alternative Communication Use by Pediatric Psychiatric Inpatients With Autism Spectrum Disorder and Interfering Behaviors. *Am J Speech Lang Pathol*. 2023 Sep 11;32(5):2040-2056. [PMID: 37433305]

Justification from IACC member who nominated article:

This study uses retrospective data (i.e., data from a previous study) to investigate the association between verbal ability and augmentative and alternative communication (AAC) use and the presence of interfering behaviors in individuals with autism who have complex behavioral profiles. The sample included 260 autistic inpatients, ages 4-20 years, from six psychiatric facilities, enrolled during the second phase of the previous study when detailed information about AAC use was collected. Measures included AAC use, method, and function; comprehension and

production of language; receptive vocabulary; nonverbal IQ; severity of interfering behaviors; and the presence and severity of repetitive behaviors. Lower language/communication abilities were related to increased repetitive behaviors and stereotypies. More specifically, these interfering behaviors appeared to be related to communication in those individuals who were candidates for AAC but who were not reported to have access to it. Although the use of AAC did not predict a decrease in interfering behaviors, receptive vocabulary scores-as measured by the Peabody Picture Vocabulary Test-Fourth Edition-were positively correlated with the presence of interfering behaviors in participants with the most complex communication needs. The communication needs of some individuals with autism may be unmet, prompting the use of interfering behaviors as a form of communication.

NIMH

Nominated article:

Day TN, Northrup JB, Mazefsky CA. A PROMIS®ing New Measure for Quantifying Emotion Dysregulation in Toddlers and Preschoolers: Development of the Emotion Dysregulation Inventory-Young Child. *J Autism Dev Disord*. 2023 Jun;53(6):2261-2273. [PMID: 35403207]

Justification from IACC member who nominated article:

The Emotion Dysregulation Inventory (EDI) was designed and validated to quantify emotion dysregulation (ED) in school-age children, with a particular emphasis on capturing ED in youth with autism. Researchers saw a need to adapt the EDI for use in young children (ages 2-5) given early childhood is a formative time for emotion regulation development. This study discussed the adaptation process for the EDI-Young Child (EDI-YC), including item refinement/generation and cognitive interviews (N = 10 with ASD), consistent with the Patient-Reported Outcomes Measurement Information System (PROMIS®) methodology. The item bank was piloted in a sample of 2-year-olds with and without autism, which provided initial support for the EDI-YC as a valid and reliable measure.

NIMH

Nominated article:

Kasari C, Shire S, Shih W, Landa R, Levato L, Smith T. Spoken language outcomes in limited language preschoolers with autism and global developmental delay: RCT of early intervention approaches. *Autism Res.* 2023 Jun;16(6):1236-1246. [PMID: 37070270]

Justification from IACC member who nominated article:

This study compared two different early intervention approaches for teaching spoken language to minimally verbal, globally delayed autistic preschoolers. Children were given an hour of therapy daily for 6 months and then reassessed 6 months later. The majority of the 164 participants were from historically excluded populations (low income and minority), and therapy was delivered in school community settings by expert clinicians. Results indicated that the participants made significant progress regardless of intervention approach: 6 months gain in standardized language scores over 6 months, but slower progress during the period after therapy ended. Children who initiated joint attention more frequently, or who had higher language understanding at baseline made more progress if assigned to receive JASPER, a naturalistic developmental behavioral intervention. Children who received Discrete Trial Training made greater language progress during 6-month period after therapy ended. These findings suggest that progress can be made in

children with autism who have very little spoken language and who receive targeted early interventions.

Services and Supports

	Services and Supports
Julie Lounds Taylor	Adams RE, Lampinen L, Zheng S, Sullivan V, Taylor JL, Bishop SL. Associations between social activities and depressive symptoms in adolescents and young adults with autism spectrum disorder: Testing the indirect effects of loneliness. <i>Autism</i> . 2023 May 22:13623613231173859. [PMID: 37212127] Justification from IACC member who nominated article: This study examined the associations between social participation and depressive symptoms among 321 autistic adults. Findings suggested that, overall, whether the adults felt that the amount of social activities were meeting their needs was more closely associated with depressive symptoms than the actual amount of time spent in social activities. Though many studies focus on the amount of social activities engaged in by autistic individuals, these findings suggest that a critical component to understanding the impact of social activities is whether the individual feels the participation is meeting their needs.
NIMH	Nominated article: Brunt S, Sadikova E, Pappagianopoulos J, Mazurek MO. The impact of COVID-19 on receipt of health services among children with and without autism. Autism. 2023 May 26:13623613231176930. [PMID: 37243353] Justification from IACC member who nominated article: The COVID-19 pandemic disrupted doctor and dental visits, mental health treatments, and other special therapies for children across the United States. Prior research has found that autistic children were more likely to lack these services even before the pandemic, but they experienced more mental health and behavior problems with the onset of the pandemic, increasing the need for these services. This study analyzed data from before (2019) and after (2020) the onset of the pandemic to determine whether autistic children had even more severe disruptions in services after the pandemic started compared to non-autistic children. They found that autistic children were more likely to have unmet medical, dental, and mental health needs in both 2019 and 2020. Overall, children experienced increased disruptions from 2019 to 2020, but this did not differ by diagnosis. The results suggest that there are persisting gaps in autistic children's healthcare regardless of the pandemic.
NIMH	Nominated article: Constantino JN, Abbacchi AM, May BK, Klaiman C, Zhang Y, Lowe JK, Marrus N, Klin A, Geschwind DH. Prospects for Leveling the Playing Field for Black Children With Autism. J Am Acad Child Adolesc Psychiatry. 2023 Sep;62(9):949-952. [PMID: 37196781] Justification from IACC member who nominated article: This study sought to examine race-based outcome disparities in autism, particularly around expediting autism diagnosis and implementing appropriate and timely developmental interventions to close the gap in intellectual disabilities (ID) comorbidities across race. Across two sites (St. Louis, MO and Atlanta, GA), black toddlers diagnosed with autism or suspected of having autism were followed for 18

months to track service acquisition and to obtain measurements of autism traits, cognitive outcomes, and adaptive function. Additionally, at the St. Louis site, families were offered autism behavioral interventions if they were unable to access services in the community. Results showed that earlier diagnosis alone did not result in more favorable cognitive outcomes for Black children with autism. Additionally, when offered the opportunity for more intensive intervention, most families pursued the opportunity. This study shows the importance of an early diagnosis coupled with timely autism specific services in addressing the prevalence gap for ID between Black and White autistic children.

NIMH

Nominated article:

Feinberg E, Stransky ML, Augustyn M, Broder-Fingert S, Bennett A, Weitzman C, Kuhn J, Chu A, Cabral HJ, Fenick AM, Blum NJ. Effect of Family Navigation on Participation in Part C Early Intervention. *Acad Pediatr*. 2023 Jul;23(5):904-912. [PMID: 37004879]

Justification from IACC member who nominated article:

Part C Early Intervention (EI) services have been shown to promote healthy development among young autistic children. However, EI participation remains low, particularly among children from structurally marginalized communities. Researchers investigated whether family navigation (FN) improved EI initiation following positive primary care screening for autism compared to conventional care management (CCM). Researchers conducted a randomized clinical trial among 339 families of children (ages 15-27 months) who screened as having an increased likelihood for autism at 11 urban primary care sites in 3 cities. Families were randomized to FN or CCM. Families in the FN group received community-based outreach from a navigator trained to support families to overcome structural barriers to autism evaluation and services. EI service records were obtained from state or local agencies. Findings suggest that FN improved the likelihood of EI participation among urban families from marginalized communities.

NIMH

Nominated article:

Kenworthy L, Childress D, Armour AC, Verbalis A, Zhang A, Troxel M, Handsman R, Kocher K, Myrick Y, Werner M, Alexander KC, Cannon L, Anthony LG. Leveraging technology to make parent training more accessible: Randomized trial of in-person versus online executive function training for parents of autistic children. *Autism*. 2023 Apr;27(3):616-628. [PMID: 35916246]

<u>Justification from IACC member who nominated article:</u>

This study compared an online parent training program for executive function intervention for autism to in-person parent training on the same content. Participants were parents of autistic children, who were between 8 and 12 years of age and did not have intellectual disability. Parents were randomized to the inperson or online training conditions. Both trainings were developed with stakeholder (parents and autistic people) guidance. Most parents reported that they liked both trainings and that they were able to implement what they learned with their children. Parents in both groups spent equivalent amounts of time (about 8 hours) with the training materials, but while 94% of parents in the in-person training attended both parent trainings, only 59% of parents in the online group completed all 10 online modules. Parents reported that it was difficult to stay motivated to complete the online trainings over the 10-week trial. Parent and child outcomes did not differ significantly between the groups. Overall, parents reported that the

trainings resulted in a reduction in their own parenting strain and improvements in their child's flexibility, emotional control, and global executive function, but not planning and organization. These findings indicated brief in-person and online training can help parents learn to support and improve their autistic children's executive function abilities, reducing their own experience of parenting strain. The finding that the online training was equivalent to the in-person trainings is important because it is accessible to parents who encounter barriers to in-person care.

NIMH

Nominated article:

Koffer Miller KH, Cooper DS, Ventimiglia JC, Shea LL. Feeling intimidated and uncomfortable: Established and exacerbated educational inequities experienced by black parents of autistic children. *Autism Res.* 2023 May;16(5):1040-1051. [PMID: 36929573]

Justification from IACC member who nominated article:

To capture the educational experiences of family members of Black autistic children as compared to white autistic children in the United States (US), a mixed methods design was implemented and included semi-structured interviews with family members of children between the ages of 5-12 who participated in a survey. The survey responses were used as attribute data. Twenty-nine interviews were conducted with parents of school-age autistic children. Findings from this study highlight challenges experienced by parents including education service use and engagement during the COVID-19 pandemic, engaging with school personnel, and securing accommodations. The findings from this study illuminate the disparities experienced by Black parents of autistic children directly reported by the parents themselves in comparison to white parents. The themes elucidated in this study have implications for policy, practice, and research to ensure equity in educational settings for Black autistic students and their families.

NIMH

Nominated article:

Roux AM, Miller KK, Tao S, Rast JE, Ventimiglia J, Shattuck PT, Shea LL. Unrealized Cross-System Opportunities to Improve Employment and Employment-Related Services Among Autistic Individuals. Milbank Q. 2023 Aug 1. [PMID: 37526044] Employment is a key social determinant of health. As such, high rates of unemployment, underemployment, and poverty across the rapidly growing autistic population are concerning. A web of publicly funded services exists to support the employment, and associated health and well-being, of United States citizens with autism and other intellectual and developmental disabilities, namely through Vocational Rehabilitation (VR) and Medicaid home- and community-based services (HCBS) waivers. Given an absence of overarching surveillance of employment services, this study aimed to characterize the distribution of autistic service users across Medicaid versus VR, understand the types of employment services utilized within these programs and expenditures, and assess overall capacity to provide employment services as needs continue to increase. This study examined the distribution of employment services among autistic people compared with those with intellectual disability using 2008-2016 data from the Centers for Medicare & Medicaid Services and the Rehabilitation Services Administration. Estimated need for employment services among autistic individuals was compared with capacity derived from VR service counts and a review of HCBS waivers. Although VR appeared to be absorbing short-term employment needs of autistic individuals,

	Medicaid was severely lacking-and losing ground-in serving those who needed longer-term employment services. VR far outpaced Medicaid in both the number of autistic people served and total expenditures across the study years. However, an estimated 1.98 million autistic adults did not receive employment services that could be critical to improving their health and well-being.
NIMH	Nominated article:
	Schiltz HK, Clarke E, Rosen N, De La Rosa SG, Masjedi N, Christopher K, Lord C. A Longitudinal Mixed-Methods Characterization of Family Support from Adolescence to Young Adulthood in Autism and Other Developmental Disabilities. <i>J Autism Dev Disord</i> . 2023 Sep 5. [PMID: 37668851]
	Justification from IACC member who nominated article:
	This study used a mixed-methods approach to examine change and stability in formal and informal family support across the transition to adulthood. Caregivers of 126 individuals with autism completed a modified version of the Family Support Scale, including open-ended questions, at five time points from adolescence (age 16) into young adulthood (age 22). Caregivers reported that informal support from family members was the most frequently used, helpful, and valued source of support with relative stability across time. In contrast, the reported helpfulness, use, and value of formal support (e.g., professionals, schools) for caregivers declined over time. Qualitative content analyses revealed characteristics of highly valued support included support type (e.g., instrumental or emotional) and features of the support source (e.g., their understanding). There was a shift to valuing emotional support more than instrumental support over time, especially for caregivers of less able adults. Partnership and dependability emerged as highly valued features of the support source. These findings fit within a social convoy perspective and likely reflect the "service cliff" experienced by autistic individuals or people with developmental disabilities and their families. As social networks shrink over time and formal services are less readily available in adulthood, remaining sources of
	support, particularly from family members, become increasingly important.
NIMH	Nominated article: Stein Duker LI, Como DH, Jolette C, Vigen C, Gong CL, Williams ME, Polido JC, Floríndez-Cox LI, Cermak SA. Sensory Adaptations to Improve Physiological and Behavioral Distress During Dental Visits in Autistic Children: A Randomized Crossover Trial. JAMA Netw Open. 2023 Jun 1;6(6):e2316346. [PMID: 37266941]
	Justification from IACC member who nominated article:
	Autistic children have poorer oral health and greater oral care challenges, which are often associated with sensory over-responsivity, than neurotypical peers. It is important to identify innovative solutions enabling dentists to successfully perform standard clinic-based procedures for this population. Researchers sought to determine whether a sensory-adapted dental environment (SADE) reduces physiological and behavioral distress in autistic children undergoing dental cleanings, compared with a regular dental environment (RDE). This randomized crossover trial was conducted at a pediatric dentistry clinic in a large urban children's hospital between May 2016 and April 2022. Each child underwent 1 RDE and 1 SADE dental cleaning, administered in randomized and counterbalanced order approximately 6 months apart. SADE included modified visual, auditory, and tactile stimuli. Findings suggest that using SADE was safe and efficacious in decreasing
	physiological and behavioral distress during dental care. This is important because

enhancing oral care is critical for autistic children; this intervention may also be beneficial for populations beyond autism.

Lifespan

NIMH

Nominated article:

Chan DV, Doran JD. Mental health counseling is rated as most helpful by autistic adults: Service perspectives in adulthood. *Autism*. 2023 Sep 7:13623613231197446. [PMID: 37679948]

Justification from IACC member who nominated article:

In this study, autistic adults provided perspectives about service use and community participation. They completed surveys, interviews, and carried a global positioning system (GPS) tracker. These participants also answered questions about which services are most helpful in adulthood, things that make it hard to use services, and what services they needed. Most participants used two services in the past 2 years: mental health and employment services. Adults who were currently seeing a mental health counselor were more likely to be working full-time and visit more locations in the community compared to those who were not seeing a counselor. Mental health services were reported as the most helpful service they received as adults, followed by employment services. These findings suggest a need for both mental health and employment services for autistic adults, as indicated by the perspectives of autistic adults themselves.

NIMH, CDC

Nominated article:

Hughes MM, Kirby AV, Davis J, Bilder DA, Patrick M, Lopez M, DaWalt LS, Pas ET, Bakian AV, Shaw KA, DiRienzo M, Hudson A, Schwenk YD, Baroud TM, Washington A, Maenner MJ. Individualized Education Programs and Transition Planning for Adolescents With Autism. *Pediatrics*. 2023 Jul 1;152(1):e2022060199. [PMID: 37345494]

Justification from IACC member who nominated article:

NIMH: This study sought to examine the contents of individualized education programs (IEPs) of adolescents with autism, including postsecondary transition goals, services, and changes in special education classification over time. This study involved a longitudinal population-based surveillance cohort from the Autism Developmental Disabilities Monitoring Network from 2002 to 2018 in 3 catchment areas in the United States. Researchers found that 92% of adolescents with autism had an IEP including a transition plan. Those without intellectual disability (ID) were more likely to have postsecondary education and employment goals and have those goals be to pursue higher education or competitive employment compared with those with ID. Forty-one percent of adolescents with autism had a postsecondary living arrangement goal. Although 28% of adolescents with autism received school-based mental health services, none of these adolescents were Black; additionally, 15% of those with ID received mental health services compared with 34% without ID. The percentage of adolescents with autism served under an autism classification increased from 44% at age 8 years to 62% by age 16.

CDC: This study identified potential gaps and disparities in educational services and transition planning among adolescents with autism, helping to guide support for

	schools and families. The contents of school-based post-high school transition
	planning are poorly understood among adolescents with autism spectrum disorder.
NIMH	Nominated article:
	Lai MC, Saunders NR, Huang A, Artani A, Wilton AS, Zaheer J, Ameis SH, Brown HK,
	Lunsky Y. Self-Harm Events and Suicide Deaths Among Autistic Individuals in Ontario,
	Canada. JAMA Netw Open. 2023 Aug 1;6(8):e2327415. [PMID: 37552480]
	Justification from IACC member who nominated article:
	This study sought to examine sex-stratified rates of self-harm events and suicide death among autistic individuals compared with non-autistic individuals, as well as
	the associated sociodemographic and clinical risk factors. In this cohort study in
	Ontario, Canada, autistic females had an 83% increased risk and autistic males had a
	47% increased risk of self-harm compared with non-autistic individuals, when
	accounting for neighborhood income and rurality, intellectual disabilities, and
	psychiatric diagnoses. The crude hazard ratio showed that autistic females had a
	98% increased risk and autistic males had a 34% increased risk of suicide death, but
	these increases were associated with psychiatric diagnoses. This study suggests that
	psychiatric diagnoses were significantly associated with risks of self-harm and
	especially suicide among autistic females and males.
NIMH	Nominated article:
	Liu S, Larsson H, Kuja-Halkola R, Lichtenstein P, Butwicka A, Taylor MJ. Age-related
	physical health of older autistic adults in Sweden: a longitudinal, retrospective,
	population-based cohort study. <i>Lancet Healthy Longev</i> . 2023 Jul;4(7):e307-e315.
	[PMID: 37295448]
	Justification from IACC member who nominated article:
	Research of health outcomes in older autistic adults (≥45 years) is scarce, and little is
	known about whether intellectual disability and sex affect the health outcomes of
	this population. The aim of this study was to investigate the association between autism and physical health conditions in older adults and to examine these
	associations by intellectual disability and sex. Researchers conducted a longitudinal,
	retrospective, population-based cohort study of the Swedish population born
	between Jan 1, 1932, and Dec 31, 1967. Their findings indicate that older autistic
	adults are at substantially increased risk of age-related physical conditions and
	injuries compared with non-autistic adults. These findings highlight the need for
	collaborative efforts from researchers, health services, and policy makers to provide
	older autistic individuals with the necessary support to attain healthy longevity and
	a high quality of life.
NIMH, Julie	Nominated article:
Lounds Taylor	Malow BA, Qian Y, Ames JL, Alexeeff S, Croen LA. Health conditions in autism:
	Defining the trajectory from adolescence to early adulthood. Autism Res. 2023
	Jul;16(7):1437-1449. [PMID: 37377040]
	Justification from IACC member who nominated article:
	NIMH: Many medical and psychiatric conditions affecting autistic individuals may
	begin in childhood, although few longitudinal studies have been conducted to
	examine prevalence rates of these conditions from adolescence into early
	adulthood. In this study, researchers analyzed the longitudinal trajectory of health
	conditions in autistic youth, compared to age and sex-matched non-autistic youth,
	transitioning from adolescence into early adulthood in a large integrated health care
	delivery system. The percent and modeled prevalence of common medical and

psychiatric conditions increased from age 14 to 22 years, with autistic youth having a higher prevalence of most conditions than non-autistic youth. The most prevalent conditions in autistic youth at all ages were obesity, neurological disorders, anxiety, and ADHD. The prevalence of obesity and dyslipidemia rose at a faster rate in autistic youth compared to non-autistic youth. By age 22, autistic females showed a higher prevalence of all medical and psychiatric conditions compared to autistic males. These findings emphasize the importance of screening for medical and psychiatric conditions in autistic youth, coupled with health education targeted at this population, to mitigate the development of adverse health outcomes in autistic adults.

Julie Lounds Taylor: This study examined frequency of physical and mental health conditions over time for autistic transition-aged youth and a non-autistic comparison group, using electronic health records. The authors examined conditions longitudinally from ages 14 to 22, which is a significant innovation as most of the research on health conditions in autistic individuals uses cross-sectional data. They found that rates of many conditions were higher among autistic youth than non-autistic youth, with increases that were similar between groups over time. Notable exceptions were obesity and dyslipidemia, which started out higher among autistic youth than non-autistic youth at age 14, and increased more rapidly among autistic youth (than non-autistic youth) over the age period under study. Findings suggest that the transition to adulthood may be a particularly pivotal time to address concerns related to obesity and dyslipidemia in autistic populations.

NIMH

Nominated article:

Ratto AB, Bascom J, daVanport S, Strang JF, Anthony LG, Verbalis A, Pugliese C, Nadwodny N, Brown LXZ, Cruz M, Hector BL, Kapp SK, Giwa Onaiwu M, Raymaker DM, Robison JE, Stewart C, Stone R, Whetsell E, Pelphrey K, Kenworthy L. Centering the Inner Experience of Autism: Development of the Self-Assessment of Autistic Traits. *Autism Adulthood*. 2023 Mar 1;5(1):93-105. [PMID: 36941856]

Justification from IACC member who nominated article:

Current tools for identifying autism are critiqued for their lack of specificity and sensitivity, especially in autistic people who are older, have higher verbal ability or significant compensatory skills, and are not cisgender boys. In this study, researchers attempted to develop a clinical self-report measure of autistic traits as described by autistic people. The measure was developed under the leadership of two autistic researchers and constructed by leveraging descriptions of autism by autistic people to generate items designed to encompass the range of the autistic experience, using strength-based, accessible language. The team utilized iterative feedback from a panel of autistic experts to refine and enhance the measure, called the Self Assessment of Autistic Traits (SAAT). It is intended for people 16 years or older and uses a format that is designed to increase its accessibility and acceptability for autistic respondents. Future work will report on the preliminary psychometrics of the SAAT, with a long-term goal of advancing our understanding of the inner autistic experience and enhancing the clinical and scientific assessment of autism.

NIMH

Nominated article:

Schiltz H, Sterrett K, Singer H, Lord C. Anxiety, depression, and well-being in autistic adults and adults with other developmental disabilities: A longitudinal cross-lagged analysis. *Autism Res.* 2023 Jul;16(7):1425-1436. [PMID: 37376983]

Justification from IACC member who nominated article:

This study sought to understand links between anxiety and depression over time in autistic adults and adults with developmental disabilities (DD), and how these conditions impact specific aspects of positive well-being. A sample of 130 adults with autism or other DDs and their caregivers were drawn from a longitudinal study. Participants complete measures of anxiety, depression, and well-being. Based on caregiver-report, anxiety symptoms predicted later depressive symptoms but depressive symptoms did not predict later anxiety; the opposite pattern was identified for self-report. Aspects of positive well-being (purpose in life, self-acceptance, personal growth) demonstrated differential links with anxiety and depression. These findings highlight the utility of a transdiagnostic approach to mental health services for autistic adults and adults with DDs, and the need to monitor for anxious or depressive symptoms in autistic adults and adults with DDs presenting with depression or anxiety, respectively.

Jenny Mai Phan

Nominated article:

Strang JF, Wallace GL, Michaelson JJ, Fischbach AL, Thomas TR, Jack A, Shen J, Chen D, Freeman A, Knauss M, Corbett BA, Kenworthy L, Tishelman AC, Willing L, McQuaid GA, Nelson EE, Toomey RB, McGuire JK, Fish JN, Leibowitz SF, Nahata L, Anthony LG, Slesaransky-Poe G, D'Angelo L, Clawson A, Song AD, Grannis C, Sadikova E, Pelphrey KA, Gendaar Consortium, Mancilla M, McClellan LS, Csumitta KD, Winchenbach MR, Jilla A, Alemi F, Yang JS. The Gender Self-Report: A multidimensional gender characterization tool for gender-diverse and cisgender youth and adults. *Am Psychol*. 2023 Jan 30. [PMID: 36716136]

Justification from IACC member who nominated article:

Given that approximately 13% of autistic individuals experience gender diversity, this study addresses a critical gap in autism research for precision clinical healthcare. This study used a data-driven approach in conducting several validity analyses using the Gender Self-Report (GSR) with 1,654 individuals (>33% autistic; aged 10-77 years). The GSR had been developed and refined though a 12-year community-driven approach. The GSR aims to give voice to individual's experiences of their gender and provides a community-developed gender advocacy tool with 30-self-report items. Results showed that there were two stable factors: Nonbinary Gender Diversity and Female-Male Continuum and found to be internally reliable. The GSR may facilitate more equitable inclusion of gender diverse individuals who do not have, understand, and/or use specialized self-descriptors for gender; this situation may be more common among autistic individuals and those with less exposure to gender diverse communities.

Julie Lounds Taylor

Nominated article:

Vincent J, Ralston K. Uncovering employment outcomes for autistic university graduates in the United Kingdom: An analysis of population data. *Autism*. 2023 Jun 23:13623613231182756. [PMID: 37353923]

Justification from IACC member who nominated article:

This is the first study, to my knowledge, to examine employment outcomes for autistic college studies. In the past, people have cited very high unemployment numbers for autistic college graduates (80%), but that doesn't seem to be based in data. In this large survey dataset of college graduates in the U.K., The authors found that rates of full-time employment for autistic college graduates were one-half what they were for graduates without disabilities. They also found higher rates of

unemployment for autistic college graduates than graduates without disabilities (15% vs. 6%), and lower pay for those in full-time positions. In contrast to previous research that showed high rates of STEM majors and jobs, showed no substantial differences between autistic and non-autistic college students in the academic programs that they were pursuing. Though the data is limited to the U.K, this study finally gives us some estimates of rates of employment and unemployment among autistic individuals who complete a college degree.

Infrastructure and Prevalence

CDC	Nominated article:
	Hughes MM, Shaw KA, DiRienzo M, Durkin MS, Esler A, Hall-Lande J, Wiggins L,
	Zahorodny W, Singer A, Maenner MJ. The Prevalence and Characteristics of Children
	With Profound Autism, 15 Sites, United States, 2000-2016. Public Health Rep. 2023
	Apr 19:333549231163551. [PMID: 37074176]
	Justification from IACC member who nominated article:
	Overall, more than one-quarter of 8-year-old children with autism met the criteria
	for profound autism. As the population of children with autism continues to change,
	describing and quantifying the profound autism population is critical for planning to
	ensure this group receives the services and supports needed during the life course
	and is appropriately represented in research and intervention studies. Further
	research on the barriers children with profound autism may face as they transition
	to adolescence and to adulthood will be important to ensure they are included in
	overall ASD services planning.
NUNALI	·
NIMH	Nominated article:
	Kahn NF, Sequeira GM, Garrison MM, Orlich F, Christakis DA, Aye T, Conard LAE,
	Dowshen N, Kazak AE, Nahata L, Nokoff NJ, Voss RV, Richardson LP. Co-occurring
	Autism Spectrum Disorder and Gender Dysphoria in Adolescents. <i>Pediatrics</i> . 2023
	Aug 1;152(2):e2023061363. [PMID: 37395084]
	Justification from IACC member who nominated article:
	Autism and gender dysphoria (GD) frequently occur together. However, past
	research has primarily used smaller samples, limiting generalizability and the ability
	to assess further demographic variation. This study sought to examine the
	prevalence of co-occurring autism and GD diagnosis in adolescents and to identify
	any demographic differences. Results showed that a GD diagnosis was more
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	prevalent among autistic youth compared to those without autism. Co-occurring
	, , , ,
	prevalent among autistic youth compared to those without autism. Co-occurring
	prevalent among autistic youth compared to those without autism. Co-occurring autism/GD diagnoses were more prevalent among youth whose electronic medical
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NIMH	prevalent among autistic youth compared to those without autism. Co-occurring autism/GD diagnoses were more prevalent among youth whose electronic medical record-reported sex was female and those using private insurance, and less prevalent among youth of color, particularly Black and Asian youth. These results could inform services that can help reduce health disparities in this population. Nominated article: Sterrett K, Magaña MT, Gulsrud A, Paparella T, Kasari C. Predictors of Attrition in a Randomized Trial of a Social Communication Intervention for Infant-Toddlers at Risk for Autism. J Autism Dev Disord. 2023 Aug;53(8):3023-3033. [PMID: 35678946]
NIMH	prevalent among autistic youth compared to those without autism. Co-occurring autism/GD diagnoses were more prevalent among youth whose electronic medical record-reported sex was female and those using private insurance, and less prevalent among youth of color, particularly Black and Asian youth. These results could inform services that can help reduce health disparities in this population. Nominated article: Sterrett K, Magaña MT, Gulsrud A, Paparella T, Kasari C. Predictors of Attrition in a Randomized Trial of a Social Communication Intervention for Infant-Toddlers at Risk for Autism. J Autism Dev Disord. 2023 Aug;53(8):3023-3033. [PMID: 35678946] Justification from IACC member who nominated article: Addressing factors that make it more likely for families to drop out of early
NIMH	prevalent among autistic youth compared to those without autism. Co-occurring autism/GD diagnoses were more prevalent among youth whose electronic medical record-reported sex was female and those using private insurance, and less prevalent among youth of color, particularly Black and Asian youth. These results could inform services that can help reduce health disparities in this population. Nominated article: Sterrett K, Magaña MT, Gulsrud A, Paparella T, Kasari C. Predictors of Attrition in a Randomized Trial of a Social Communication Intervention for Infant-Toddlers at Risk for Autism. J Autism Dev Disord. 2023 Aug;53(8):3023-3033. [PMID: 35678946] Justification from IACC member who nominated article:

university-based randomized controlled trial of two 8-week long early intervention programs. Overall, attrition (i.e., dropping out of a study) through 8-weeks was low, approximately 13%, however by the one-year follow-up attrition rates were approximately 50%. The most consistent predictor of attrition was the distance that families had to travel to the university. These data highlight the importance of providing services and support (e.g., financial and logistic) during follow-up to families to maximize their participation.